Concepts of trust among patients with serious illness

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Abstract

This paper examines conceptions of trust among three groups of respondents diagnosed with either breast cancer, Lyme disease or mental illness. Interviews were carried out using an open-ended interview guide to explore how patients made assessments of trust in their doctors and health care plans. The guide followed a conceptual approach that asked questions about competence, agency/fiduciary responsibility, control, disclosure and confidentiality. Respondents were given ample opportunity to raise other areas of concern. The data were organized using the NUDIST© software package for the analysis of non-numerical and unstructured qualitative data. Patients viewed trust as an iterative process and commonly tested their physicians against their knowledge and expectations. Interpersonal competence, involving caring, concern and compassion, was the most common aspect of trust reported, with listening as a central focus. Most patient comments referred to learnable skills and not simply to personality characteristics. Technical competence also received high priority but was often assessed by reputation or interpersonal cues. Patients were much concerned that doctors be their agents and fight for their interests with health care plans. Disclosure and confidentiality were less common concerns; most patients anticipated that doctors would be honest with them and respect their confidences. Patients’ responses also appeared to vary by their disease, their socio-demographic characteristics, their involvement with self-help groups, and how their illness conditions unfolded. © 2000 Elsevier Science Ltd. All rights reserved.

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Trust is fundamental to effective interpersonal relations and community living. To be without trust requires continuous vigilance and anxiety or necessitates reclusiveness. For the most part, individuals relate to others on the assumption that people generally are who they purport to be, will act in accordance with generally understood norms of behavior and will meet their role obligations. But it is also recognized that people violate trust, fail to perform as expected and commit fraud. To protect against such violations in consumer and professional interactions, we have developed a wide range of instruments, including licensing, certification and other regulatory arrangements, that allow people to go about their affairs more comfortably (Shapiro, 1987). Trust is always a prediction about the future (Luhmann, 1989), and maintaining it requires some balance between risk and protective arrangements.

Social interaction is an iterative process and individuals build trust over time in their interactions with particular others. Trust is much stronger in families and close friendship networks than in less primary interactions because the mutual relationships set powerful constraints on violating trust (Barber, 1983). However, there are circumstances where people are required to...
put trust in persons they may not know or only know casually and where misplaced trust can have great consequences. One such area is that of doctor–patient relationships involving patients who have serious and complex illnesses characterized by uncertainty. How such patients make trust determinations and test trust-worthiness reveals important dynamics of the trust relationship.

With major changes in health care organization and the growth of managed care, the erosion of trust has become a growing concern among medical managers and the general public (Mechanic, 1996). Surveys indicate that public trust in medical leaders has significantly diminished (Blendon, Hyams & Benson, 1993) and, although most patients continue to trust their personal physician, a recent survey found that 47% of insured respondents and 61% in “heavy managed care” were very worried that their health plan would be more concerned about saving money than about what is the best treatment for them when they are sick (Blendon et al., 1998). This opinion, of course, reflects social trust in health plans and not interpersonal trust in physicians but it is difficult to believe that with changing medical arrangements such attitudes do not spill over to interpersonal trust between patient and doctor. This exploratory study of patients with three serious medical conditions was carried out to obtain greater insight into the dynamics of trust and to identify concepts that need development in surveys with more representative samples.

**Exploratory study design**

In this study we interviewed 90 patients, 30 each from three illness groups: breast cancer, chronic Lyme disease, and mental illness. Each of these illnesses is characterized by its severity and the uncertainty of its prognosis, characteristics that we believe are likely to contribute to intense relationships with physicians and increase the saliency of trust in the relationship. The breast cancer subjects were all recruited from a treatment/research center that exclusively treats cancer patients. In order to be eligible for the study, women had to have been diagnosed with breast cancer, have been post-surgery and, if applicable, have undergone at least some of their chemotherapy and/or radiation treatments. These criteria were established to ensure that the subjects had a certain amount of experience with the particular physician who was treating them. Furthermore, patients who had been through at least part of their treatment were thought to be less likely to be in the midst of the crisis that can occur around diagnosis and that might make it difficult for them to think clearly and meaningfully about the subject of trust. Physicians and nurses at the cancer center identified potential subjects from among their patients, gave them information about the study, and asked them to participate.

The majority of the Lyme disease respondents were recruited from self-help groups not affiliated with any hospital or medical clinic. The study was described at a meeting of the self-help group or information was provided through the group’s website and members were asked to participate. Additional Lyme disease patients were recruited by word-of-mouth (3 patients) or through a Lyme disease clinic at a local medical center (2 patients). In order for Lyme disease patients to be included in the study, they had to have been diagnosed with Lyme disease by a physician and had to have had a minimum of two visits with a physician who was treating them, again, to ensure they had a basis for their comments on trust in the relationship. The patients with mental illness were recruited through a community mental health center and had to have a serious mental illness (i.e., major depression, bipolar disorder, schizophrenia or schizoaffective disorder, or a serious anxiety disorder) for which they were being treated by a psychiatrist whom they had seen at least twice.

Potential subjects were excluded if there was evidence of physical, mental or emotional inability to complete the interview. None of the potential subjects in either the breast cancer or Lyme disease groups were excluded from participating. Interviews were initiated with six psychiatric patients but were stopped before completion because the patients’ thought disorders or delusions made it impossible for them to provide appropriate responses to the interview questions.

The study, interview protocol, and consent processes were reviewed by the Rutgers University institutional review board (IRB) as well as by the IRBs of the University of Medicine and Dentistry of New Jersey (UMDNJ) and the Cancer Institute of New Jersey (CINJ), which were the sources from which some subjects were recruited, as described above. The interviews followed a semi-structured protocol that queried patients about various aspects of their interactions with their physicians, medical institutions and health care plans. The interview questions were derived from a literature review and were intended to access a broad range of information that could potentially affect a person’s level of trust. The questions were open-ended to allow the subject to describe, in his or her own words, the most salient or meaningful aspects. The belief was that the open-ended format could provide information not currently available about how patients view trust, their expectations and assumptions about trust, and processes of deciding whether and how much to trust. Subjects were asked to talk about the physician they were currently seeing, but were free to...
introduce thoughts about other physicians they had dealt with, since a particularly good or particularly bad experience with one physician could affect a patient’s inclination to trust other physicians.

All interviews were conducted by a single interviewer, a clinical psychologist with experience conducting qualitative interviews. The interviews were audiotaped and transcripts prepared from the tapes. Transcripts were imported into the Qualitative Solutions and Research (QSR) NUDIST software package, that aids in the data management and analysis of non-numerical and unstructured qualitative data. In analyzing the data, subject responses were broken down into individual phrases that expressed a single idea or theme. Each phrase was then coded according to the type of information it presented. A single phrase could be coded multiple times, if it were relevant to more than one topic. Codes, which specified dimensions of trust like technical competency, interpersonal competency, confidentiality, etc., were initially created based on the literature review. As the analysis proceeded, additional codes were added as they were extracted from the themes and ideas in the transcripts. In addition to analyzing the transcripts based on the codes assigned, word counts were also conducted to determine the frequency with which the phrases referred to particular words.

Coding reliability was established initially by having transcripts coded by multiple coders and comparing the codes. A coding manual was developed, training was provided and coders practiced coding on a number of transcripts before the actual coding took place. Three individuals were involved in coding the transcripts and a conservative approach was taken to establishing agreement. Any code for which there was not agreement by all three coders was discussed; if agreement could not be reached, the code was not assigned. Once reliability was established, as indicated by consistent agreement among the coders, transcripts were coded by individual coders. Reliability checks were then conducted periodically to ensure that reliability was maintained.

Socio-demographic characteristics of subjects

Due at least in part to the different contexts from which they were recruited, the three groups differed significantly in their demographic characteristics (see Table 1). These differences probably contributed to some of the variations in their views on trust. All breast cancer patients were female; in the Lyme disease group, twenty-five of the thirty respondents were female; and fourteen, a significantly lower number, of the patients with mental illness were female. In terms of age, subjects in the breast cancer group ranged from 35 to 76 years old, with a mean of 55.9 years; the Lyme disease group ranged from 29 to 74 years old, with a mean of 48.3 years; and the somewhat younger mentally ill group had an age range of 19–64 years.

Table 1
Demographic characteristics of sample

<table>
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<tr>
<th></th>
<th>Breast cancer</th>
<th>Lyme disease</th>
<th>Mental illness</th>
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<td># Other</td>
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* t-test: differences between LD and MI, BC and MI are significant at the 0.05 level.
† ANOVA on exact age: differences between BC and LD, BC and MI are significant at the 0.05 level.
‡ ANOVA on <h.s. vs ≥h.s.: differences between MI and BC, MI and LD are significant at the 0.05 level.
§ ANOVA on white vs other: difference between LD and MI is significant at the 0.05 level.
with a mean of 42.6 years. The mean age for the breast cancer group was significantly different from the means for the Lyme disease and mentally ill groups. The breast cancer patients were the most highly educated of the three groups, with seven subjects having advanced degrees, eight others who completed college and only three who did not finish high school. The Lyme disease group differed slightly, in that only two had advanced degrees, but 14 in this group completed college and only one did not graduate from high school. In contrast, the mentally ill group was significantly different from the other two groups in the proportion of subjects who did not complete high school. In this group, two subjects had advanced degrees and five others completed college, but there were ten who did not finish high school and an additional two who did not complete grammar school. In terms of race, five patients with breast cancer and only one with Lyme disease were African–American; the rest in both groups were white. Of the patients with mental illness, six were African–American, two Latino and twenty-two white. Only the difference between the Lyme disease and the mentally ill groups was significant in terms of race. Patients were not asked about their income levels, but it was apparent to the interviewer that the breast cancer and Lyme disease groups were primarily middle class, whereas the psychiatric patients were a mix of middle and lower class.

**Biases**

There are several biases inherent in this study. First, the three samples were recruited from different clinics and patient self-help groups and are not representative of all such patients. For example, members of self-help groups are self-selected and tend to be more involved and vocal than patients generally. Since recruitment differed by group, comparisons across groups may reflect such differences. Second, the interview schedule followed a conceptual view of trust that helped frame the questions asked. Both the number and types of questions asked about a particular aspect of trust might affect the responses and word counts for that dimension. Third, patients reported on a variety of retrospective experiences occurring at varying points in time. Such reports may be biased by recall problems and retrospective reconstructions of events. Despite these limitations, patient interviews provide a richer basis for understanding how patients conceive of trusting relationships with their doctors in important medical encounters than would be accessible from a standard trust survey.

**Dimensions of trust**

Our interview guide asked questions about the five dimensions of trust derived from our conceptual approach: competence (technical and interpersonal); fiduciary responsibility and agency; control; disclosure; and confidentiality (Mechanic, 1998a,b). The interviews enhanced our understanding of how patients construed these varying areas and how interpretations may differ among different patient groups. In addition, other dimensions of trust became apparent as the interviews were analyzed. We will explore whether they can be fruitfully incorporated into the hypothesized conceptual areas or should constitute separate dimensions. The discussion that follows examines each dimension in turn as well as the relationships among dimensions. We begin the discussion, however, with our respondents’ characterizations of trust.

**Patients’ concepts of trust**

We asked each respondent the question: What does trust mean to you? This elicited a variety of responses, some of which cut to the core of trust — such as the indication that trust allows accepting vulnerability, or the belief that the other has one’s best interests at heart. The answers ranged across our conceptual dimensions including those of competence, agency and confidentiality. The concepts of control and disclosure, which we will explore later, were rarely mentioned in these unstructured responses, although it could be argued that disclosure was conceptually included when themes like truthfulness and open communication were mentioned. In contrast, caring (which we included under interpersonal competence but which may more fruitfully be considered a separate category) was a frequent theme. Themes that were most common included honesty, openness, responsiveness, having one’s best interests at heart, and willingness to be vulnerable without fear of being harmed. The following indicate something of the range of responses:

Trust means that there’s confidence in a person. That I know they’ll do the right thing that’s in my best interests. That the person’s well trained. That they’ve had previous experience working on this particular type of medical problem. And that they’re up-to-date on the latest technology, latest research. And that they treat you as an individual, as opposed to just another patient. . . . (Technical Competence, Interpersonal Competence, Agency/Fiduciary Responsibility)

Trust...I think, is something that comes over a period of time. Trust means essentially you would trust a person with your well-being...and in the
absence of being able to control the situation, you would trust this person to control it in your best interests as well as they could. (Agency/Fiduciary Responsibility, Control)

Trust...means compassion; it means listening and really hearing...It's just dedication. (Caring)

It’s knowing that what you tell a person is going to stay with that person. (Confidentiality)

Making trust calculations

Trust, as we have emphasized, involves vulnerability and people typically proceed cautiously when the possibilities of harm are significant. Trust builds iteratively through experience and this explains the greater trust in long-term than short-term medical relationships (Kao, Green, Davis, Kolpan & Cleary, 1998a; Kao, Green, Zaslarsky, Koplan & Cleary, 1998b). People vary in their initial willingness to trust, but most begin with the assumption that most doctors are competent and appropriately motivated. Medical relationships are often initiated on the basis of recommendations of family and friends, so trust initially may be based on reputation. We asked our respondents: How do you decide that a person can be trusted? Patients often have a difficult time articulating how they make such decisions. They sometimes refer to intuition or gut feelings, but their responses made it reasonably clear that they typically test the doctor’s responses against their expectations and feelings about what would be most appropriate. The concepts that most commonly occur in their descriptions of deciding to trust include testing the doctor, observing the doctor’s actions, assessing their experience with him or her, and evaluating how treatment is proceeding in terms of results and outcomes. Some examples from the interviews illustrate these approaches:

Well, first of all, if I hit them with something, I see how they come back at me. If they evade the issue or they ignore it or something else, then they’re not to be trusted. Even if they don’t give me the answer I want, if they give me an answer that is forthright, then I can trust them. (Testing)

So I think it’s a relationship that takes a little bit of time to see how things work on both ends. How you respond to the doctor, how the doctor responds to you, and how you feel at the end when the treatment is over. (Experience)

I guess when I watched her she handled different people differently. And she had taken the time, as
had the other doctors, to figure out who I really was. And once they did that, then we could have open communication and that’s where trust comes from... (Observing)

I’m a pretty trusting person when it comes to people in general. I think I just have a wait-and-see attitude. I trust somebody until they do something I realize was untrustworthy. (Until proven otherwise)

Over time. Many conversations with them. Putting them to the test. Having an incident that may be ugly or embarrassing... If I’m in a situation and I can pass information on to them and know that I’m still safe... (Testing over time)

Interpersonal competence

Competence of the physician is of primary importance but patients have limited capacity to evaluate the technical competence of doctors. Thus, it is no surprise that in discussing trust they put the most emphasis on interpersonal competence. Thom and Campbell (1997) ran focus groups, with 29 participants from three practice sites, exploring the meaning of trust. They identified seven categories of physician behavior that promote trust, five of which were interpersonal (understanding patients’ individual experiences, caring, communicating clearly and completely, building partnerships and honesty with respect for the patient). We think of this dimension as a type of competence, rather than simply labeling it caring or kindness, because we believe that most of the behaviors associated with it are skills that can be initially taught and corrected when defective (Roter & Hill, 1993; Scott, Aiken, Mechanic & Horavcsik, 1995; Suchman, Markakis, Beckman & Frankel, 1997). There are, of course, personality aspects, like warmth and empathy, that may not be taught as readily but we are impressed by how often the interpersonal aspects patients feel strongly about are teachable.

Of the 18,975 phrases we coded, 939 could be described as interpersonal competency. We also identified an additional 157 phrases referring to caring which arguably may or may not be thought of as competence. In contrast, only 569 phrases referred to technical competence and these were often more vague. Patients made an average number of 10.4 comments about interpersonal competency but the average for technical competency was only 6.3 (see Table 2). Patients in the study were seriously ill with much experience with doctors and, thus, we would expect them to say much more about technical competence than patients with more limited medical experience. Indeed, some had researched their illnesses very thoroughly, yet the interpersonal dimension dominated.

A large number of words were used to describe interpersonal competence, but the most prominent concept involves listening. Other very commonly used descriptive words were caring, concern, and compassion. The evidence that patients were often referring to skills as compared with personal traits is supported by concepts they commonly referred to: abrupt, arrogant, attentive, condescending, distracted, eye contact, friendly, truthful, non-judgmental, patronizing, professional, reassuring, respectful, responsive, sensitive, sincere, warm and understanding. Other important interpersonal skills were less commonly mentioned: direct, distant, rushing, flexible, interested, nurturing, patient, rigid, etc. The quotes that follow convey the types of interpersonal processes of particular relevance to patients:

I need understanding, empathy, concern about me as a total person, not just about my disease. I need concern about my fears, how I’m managing with my life — my family life, my work life, and how I’m able to keep it all together. I need the doctor to express some level of empathy; ask some questions that are not necessarily medical... “how is this affecting your work? How are you handling your family responsibilities?”

I look for someone who’s willing to listen — who listens to what I have to say and asks what I consider appropriate questions, asks for additional information. And kind of gently leads me to the point where I give him the information that he needs.

I think that I want somebody who will listen... somebody who looks at me as a person and not so much as statistics or a number, somebody who shows me that they understand, they’re sensitive, they care.

Technical competence

Patients generally refer to technical competence by noting the physician’s experience, thoroughness, and knowledge. They use a wide range of words to denote competence involving education, credentials, expertise and intellectual capacities. When they refer to specific behaviors, they use such words like double-checks, always thinking ahead, has newer information, keeps current, keeps up on new studies. Assessment of technical competence is often based on experiences and how patients feel their illnesses are progressing under
treatment (wasn’t getting better, gave wrong medication, made matters worse, misdiagnosed, should have picked up on; or, more positively: can diagnose, knows how to help, prescribes the right things). Patients have different levels of knowledge and resourcefulness in learning about their disease, and frequently consult alternative sources of information. These establish expectations about the nature of technical competence and its manifestations, which are then compared with their experience as it unfolds. Some of the following quotes illustrate these points.

I fired a doctor not long ago because he was an alarmist and I don’t need that. I had a lump that I discovered...and he said, “well, it can be pancreatic cancer or liver cancer”. And I thought, “Geez, that means I’m dead between the next six months”. It turned out to be an umbilical hernia. And that’s the last time I ever went to see him. He’s a fool. They don’t always graduate at the top of their class in medical school.

He’s very good about prescribing pills and stuff. The pills he gave me, they work on me perfectly...He’s a very good doctor.

...she’s a fine physician and she is even going to be a finer one. I think she has some developing to do...she is on the right track, but there are some things that only experience and time can give you and she doesn’t have those on her side yet.

And I said, “There’s been a 25 pound weight loss in a two month time span”. The liver enzymes at that point were, like, double what they should have been. They were heading very high. And I just said to them, “Don’t put your incapabilities and guilt on me. Cause I don’t take it”. And I said, “If you can send in a psychiatrist who can bring down liver enzymes, then we’ve got it on target. Until then, you just haven’t found a diagnosis”.

Agency/fiduciary responsibility

Physicians have had an ethical responsibility to serve as agents solely of their patients and to do their best to promote patients’ best interests. Much of the present controversy about changing roles and financial incentives with managed care focuses on the erosion of physician advocacy for their patients and increasing responsibilities for allocating services (Mechanic & Schlesinger, 1996). Although these conflicts have been evident for some time, patients often do not understand these shifts and find the idea of their personal doctor weighing their needs against other interests difficult to accept. But they also understand that their doctors may have difficulty prevailing against administrators of large health care plans. Most patients, regardless of their health insurance arrangements, want to believe that their interests are primary and that their doctors would do everything possible to serve them as needed (Mechanic, Ettel & Davis, 1990). Commitment to the patient and patient advocacy are common themes in patients’ concepts of trust. Common phrases used include advocates, argues for, defends, does everything in their power, in my best interests, fights for, doesn’t give up, never stops trying, on my side, sticks up for you, puts self on the line, and so on. Some illustrative quotes follow:

I think they shouldn’t have anything to do with the health plan or the payment. They should just deal with the patients according to the oath they took.

My primary care physician. ...I don’t know him well enough, (but) I would hope that I could have the confidence that he would fight for me. But then again, I don’t think he would jeopardize his position with the HMO and I don’t trust — trust — that he would.

I think my doctor would fight if she thought that she was going to get results.

I spoke to an oncology social worker who was a friend, when we first started this...and she said that a lot of the health care people who have to deal with Dr. X are not ecstatic with her because of the fact that she is a patient advocate. And I thought, “Tough!” That’s exactly what I want in my corner.

Control

With the growth of managed care, patients are learning that despite physician advocacy their doctors are not necessarily able to control their pattern of care and what treatments they get (Blendon et al., 1998). Anderson and Dedrick (1990), studying outpatients at a Veteran’s Administration medical center, found that patients who were less trusting wanted greater personal control but when trust was high they scored higher than those with low trust on a scale of desire for clinicians’ control. While agency can mediate control, as in the case where high agency on the part of a physician results in greater control over a patient’s case, the control that doctors have is being reduced by the financial and administrative control mechanisms of health care
plans. This is still a relatively new concept for many patients, but patients who are seriously ill increasingly encounter the battle between their treating physicians and health care plans. They increasingly understand that physicians under managed care face constraints, are controlled, interfered with, denied, dictated to, pressured, limited, restricted and hassled. With greater awareness, there is increased uncertainty whether their doctors can get them what they need. Although some patients have already had such experiences, for most it remains a hypothetical concern about their future care.

I have seen doctors dictated to and their treatment changed because of the way health insurance is now.

I think a lot of doctors today...they have to call the insurance before they can even say, “Go do this” or “Do that”. So it does affect how they are treating you. Certain things aren’t allowed by the insurance companies.

I have a situation where I am in need of medical tests and it’s been two months now, since the insurance company’s been advised and they have yet to give any approval. And this doctor has just pointedly told me, “I don’t give a squat about your condition. Unless I get paid, I’m not doing anything”.

Confidentiality

Patients reveal private matters to physicians that they would not reveal to spouses, relatives and intimate friends. The physician role also makes permissible asking questions that in other circumstances might be seen as intrusive and offensive. Patients generally assume that what they tell their doctors is protected, although they may censor information consistent with the amount of trust they feel. With the increased penetration of managed care and the sharing of personal information with utilization reviewers and health plans, the risks increase that embarrassing and damaging information will be more widely available and confidentiality more easily breached. Nevertheless, confidentiality does not appear to be a predominant issue in reports about trust and most patients believe that their personal doctors maintain their confidences.

Patients with stigmatized illnesses may also be concerned about computer records that may be available to persons other than their personal doctors (Rochefort, 1996), but personal experiences with such issues did not come up in our interviews. We did, however, observe that issues of confidentiality were most common among patients with psychiatric illness and least common with Lyme disease patients. In referring to confidentiality, patients use such terms as private, in confidence, with permission, blabbed, use my name, and the like. Further, patients seemed to be realistic about limits on the ideal of confidentiality.

...there is absolutely nothing in this world private, totally private, anymore. So I don’t worry about it. It’s going — somebody has access one way or the other.

A doctor isn’t no different than, you know — because we’re all human beings and people like to talk.

This is a small town; you know a lot of people that work in the doctor’s office and what I’ve noticed at this practice is that there’s a large turnover in staff. And I wouldn’t doubt that some of it has to do with the fact that, maybe, these people are not keeping their mouths shut.

Disclosure

Issues involving disclosure about physician incentives, conflicts of interest, and constraints by health plans on physicians exploring different treatment options were not familiar to most patients. When asked specifically how they feel about physician incentives, patients expressed repugnance at the idea that their physicians might limit treatment or tests for personal gain. Despite the strong feelings expressed about incentives, however, most respondents did not feel it appropriate to ask a physician about pay structure and the effect that might have on his or her medical decisions. Failure of a physician to disclose conflicts of interest was questioned by some patients, both in terms of referring patients to a facility in which the physician had some financial interest and allowing HMO policy to dictate treatment. However, as noted above, patients were aware that their doctors often had to answer to health plan managers so that their attempts to advocate for the patient might not prevail. Statements illustrating disclosure issues include:

I don’t know if they get (paid) more for that or special points or something. But that was one of the things that entered my mind when she was pushing for the protocol...she didn’t tell me that she was getting paid...she didn’t tell me any details about it.

...a doctor writes a referral, like for an upper GI, and they want you to go to one of their places. And you call the hospital and find out it’s so much
cheaper or that they accept insurance and the other place doesn’t.

...situations with the insurance where they’re not allowed to discuss, as an example, certain options because the insurance company will not allow them. I’m aware of that practice and I make it very clear to the doctor when I go in, “I don’t know what’s going on with Medicare or whatever, or if it’s the situation here, but you better tell me everything that I need to know”.

The problem I’m having today, and it really annoys me, is you can’t get information easily about a doctor’s background.

Major differences among illness groups

There were some noteworthy differences among the three patient groups in the emphasis placed on different aspects of trust, as can be seen in Table 2. As noted in the previous discussion of the study design, the different means by which each group was recruited could account for some of the differences found. Further, the groups’ demographic characteristics are dissimilar which could also contribute to appreciable differences, as discussed below. Despite these potential biases, it appears that some of the differences among groups can be attributed to the ways in which characteristics of the illnesses themselves interact with the development of trust.

The group suffering from breast cancer appeared to have the highest overall level of trust. This is a subjective judgment based on greater positive responses to the questions posed. Such positive comments most frequently pertained to issues of technical and interpersonal competency and caring. The breast cancer subjects did not make the most comments for these dimensions, but the proportion of the comments they made which were positive was higher for this group than for the other groups. While it could be argued that these results are primarily due to the fact that this group was being treated by specialists in a university medical school center devoted to the treatment of cancer, it is also likely that the life-threatening nature of the disease makes it more important to these women to feel that they can trust their physicians.

The respondents in the Lyme disease group, in talking about the meaning of trust, were more likely to mention the importance of being able to be open with the physician without fear of being judged or ridiculed. They also put more emphasis on the feeling of vulnerability inherent in the interaction. A related issue, that of being rejected by the doctor (either literally or implicitly), was mentioned almost exclusively by this group. Each of these factors contributed to a mean phrase count for the Interpersonal Competency dimension that was significantly greater for the Lyme disease group than the mentally ill group, but not significantly different from the breast cancer group. The Lyme disease group also emphasized the importance of the physician being able to admit lack of technical knowledge or competency in a particular area. This is reflected in the significantly greater frequency with which the Lyme disease subjects talked about technical competency, as compared to either of the other groups. The mean number of comments for the Control dimension was also significantly higher for the Lyme disease group than either of the other groups. It is likely that this is a result of the experience reported by many of these subjects of having the treatments recommended by their physicians denied by their insurance companies. Finally, these subjects talked about loss of trust and not trusting their physicians more than twice as much as subjects in either of the other two groups. These outcomes could be attributed at least in part to the uncertainty inherent in the diagnosis and treatment of Lyme disease, as well as to the experience reported by the majority of these subjects of being doubted, criticized, ridiculed and rejected by physicians they consulted.

One of the factors that seemed particularly important to the respondents with psychiatric illnesses was the physician’s knowledge of, and efforts to minimize, the side effects of medications. Respondents in this group emphasized the importance of trusting a doctor enough to be able to speak openly about the side effects they experienced. This is an especially sensitive area for them since the side effects are often of a sexual nature. This group also focused on issues of confidentiality to a degree that was significantly greater than for the breast cancer group, but not the Lyme disease group. This focus is not unexpected given the stigma generally attached to mental illness and the explicit attention paid to discussing confidentiality and signing releases that one generally sees in these settings. The significantly lower frequency with which the mentally ill subjects talked about the interpersonal competence of their physicians could also be attributed to aspects of their illness and the stigma attached to it. Finally, the patients with psychiatric conditions, more than either of the other groups, reported withholding various types of information from their physicians, such as their use of substances, the nature of side effects they were experiencing, dangerous behaviors they were engaging in, or the fact that they were taking more or less of their medications than prescribed. They
Di/C128erences by patient characteristics

Clearly, the differences among groups are likely to have contributed to the variation in the type of comments and the relative frequency with which different aspects of trust were mentioned by each group, as was illustrated in Table 2, and this should be considered when viewing the study results. That the thirty patients with mental illness had substantially less to say overall (5642 total phrases for their interviews as opposed to 6371 and 6962 total phrases for the breast cancer and Lyme disease groups, respectively) could be attributed to a combination of the effects of the illness and the socio-demographic composition of the group. One outcome of the study that is likely to be directly related to these socio-demographic variations is the difference in the frequency with which outside sources of information were noted. Respondents in both the breast cancer and Lyme disease groups often spoke about information they had obtained from a media source or the Internet. The Lyme disease patients, in particular, perhaps as a result of sharing information in their self-help groups, regularly referred to information obtained from sources other than their physicians. There were very few such references made by psychiatric patients. This contrast could be attributed to the higher education level of the other two groups and their familiarity with, and comfort in using, other information sources.

Self-help group vs clinic patients

Respondents were not specifically asked about their membership in self-help groups, so we do not know how many of the breast cancer or mentally ill subjects belonged to such groups. It is clear, however, that the Lyme disease respondents, largely recruited from self-help groups, were more focused on issues of advocacy, and getting and sharing information about physicians, insurance coverage and treatment approaches. In their comments on trust, they placed a greater emphasis on the importance of physician agency in “fighting for patients’ rights” and issues pertaining to control of the doctor by insurance companies. This can be seen in Table 2, where the mean phrase counts for Agency/Fiduciary Responsibility and Control are higher for the Lyme disease group than the other groups. Further, it is possible that the empowerment fostered by self-help groups contributed to higher expectations against which they judged their physicians.

The clinic setting that was the source of patients with mental illness is likely to have contributed to the greater emphasis given to issues of time and continuity in their comments. For this group in particular, their comments about time were focused on not having enough time with the physician, in contrast to the breast cancer patients who were generally satisfied with the amount of time they had or the Lyme disease respondents’ complaints about time spent waiting for the doctor. This group also seemed to have difficulty trusting their physicians because of the lack of a long-term relationship with a single physician, as may have been reflected in their lower mean number of comments on interpersonal competency. Those who were able to stay with one physician long enough to develop an on-going relationship seemed less likely to indicate a lack of trust. Unfortunately, patients in the mental health clinic seem not only to lack the opportunity to choose a particular physician, but also are subject to the frequent changes in psychiatrists that seem to characterize many such clinics.

Discussion and conclusions

There are tangible clinical, economic, and ethical consequences when trust is undermined. A major way of countering this and building patient trust is to provide opportunities for patients to select their health plans and physicians (Kao et al., 1998a,b). The market transformations brought about by more restricted choices and the growth of more rigorous managed care affect patient trust. In respect to the former, almost half of employees in large firms and four-fifths of employees in small firms can choose only one plan (Gabel, Ginsburg & Hunt, 1997). Moreover, as managed care becomes more rigorous, patients are increasingly worried about the care they will receive when they are sick (Blendon et al., 1998). As trust diminishes in health care plans, trust in physicians becomes even more important, going beyond the therapeutic alliance and the facilitation of appropriate communication and treatment compliance. Patients now have to be concerned about whether their physicians will fight to get them what they need and how much control the physician has over their pattern of care. Given the importance of trust for effective medical care, identifying structural arrangements and training approaches that facilitate doctor–patient trust is critical (Mechanic, 1998b; Mechanic & Rosenthal, 1999; Suchman, Botelho & Hinton-Walker, 1998).

While we approached our explorations of trust with three patient groups around our five-fold conceptual approach, there was ample opportunity for patients to bring other issues to our attention. There were no major surprises although the emphasis patients put on different dimensions varied by disease group and...
patient characteristics. Although we thought of caring as an area somewhat separate from trust, or part of interpersonal competence, it comes through in the interviews as a more general concern and important feature by which patients assess whether the doctor is trustworthy.

The area of competence is particularly central to trust. Patients understand that technical competence varies in doctors but are limited in the ability to assess it. For the most part, they use commonsense approaches such as those based on assessing qualifications and status (specialist, medical school doctor, researcher) or on whether events proceed in an expected or preferred way (they feel better, the medications help). In contrast, patients are quite skillful at observing interpersonal competence in a detailed fashion (Roter & Hall, 1993) and they have many more ways to describe it. They often use cues about interpersonal competence as an indication of technical competence although they understand that a good “bedside manner” does not necessarily denote diagnostic and treatment abilities. These are themselves not surprising observations. What may be less appreciated, however, is that patients are making observations of concrete behaviors that are not simply “art”, as much of the traditional literature would suggest, but teachable skills. The behaviors of importance to patients — listening carefully and providing responsive feedback, minimizing interruptions, maintaining eye contact, conveying understanding of patients’ distress and vulnerabilities — are skills that can be taught. This is true, as well, of many aspects of caring which can be conveyed, for example, through the appropriate use of touch or by making inquiries on issues of concern to the patient. Moving beyond the individual clinician, it is often possible to establish clinic practice routines that reduce errors, facilitate communication and insure appropriate feedback, instruction and follow-up (Scott et al., 1995).

Competence was salient for all patients, but patients varied more in their emphasis on other areas of trust. Among these other dimensions, agency was more commonly referred to than control or disclosure although questions were asked in each area. Generally, unless patients had confronted a problem in these latter areas, or were familiar with others who had, they assumed that physicians would behave appropriately. Patients with Lyme disease who had encountered more difficult problems in their care, or who had experienced denials of care from their insurance plans, appeared more vigilant and critical although this may also reflect selection effects in this subsample.

Patients understood that confidentiality was sometimes not respected but in this area they generally trusted their physicians. Patients with mental illness referred more often to confidentiality, probably reflecting concern about stigma. This does not appear to be an area of immediate concern for most patients because most assume the physician’s discretion; but the same confidence does not always extend to other staff. As managed care requires more sharing of confidential patient information and more perceived risk of violations of confidentiality, concern may grow.

Most discussions of trust treat it as a general concept but the salience of trust and its various dimensions depends very much on the patients’ circumstances, the extent they feel at risk, the particular characteristics of their illnesses and needs, and their level of sophistication and access to information. Patients have varying stakes in their medical encounters. Those with Lyme disease who often feel that their illnesses have not been validated by physicians, and resent the common implication that their chronicity is emotional in nature, seem to “test” their doctors more aggressively than others. Such behavior is probably more characteristic of patients with controversial complaints (Sigal, 1996; Ciba Foundation, 1993) and diagnoses such as chronic fatigue syndrome, chronic myalgia, chemical sensitivity disorders, and Gulf War syndrome, than it is of patients whose vulnerability rests in the uncertainty in the outcome of their disease and treatment as in breast cancer. Patients with psychiatric disorders, in contrast, feel vulnerable not only because of the uncertainty associated with their disorders but also due to the significant risks of stigmatization, embarrassing side effects and rejection.

In emphasizing the importance of trust, we do not suggest that patients should trust blindly. Patients and professionals both need better preparation for establishing effective therapeutic alliances (Coulter, Entwistle & Gilbert, 1999; Frankel & Stein, 1996; Roter & Hall, 1993). Patients have to be better informed and more skilled at using information about their health plans, doctors, and illnesses. Although there is great emphasis on providing more such information to patients, most of it poorly corresponds to patients’ conceptions of their needs (Coulter et al., 1999; Hibbard, Slovic & Jewitt, 1997). Moreover, most patients do not depend on expert sources of information. Respondents, for example, give more credence to the experience of friends and family in choosing a hospital than to the evaluations of experts (Robinson & Brodie, 1997). From a professional perspective, trust-building and caring are technologies that can be developed both through organizational strategies and through individual skill development (Scott et al., 1995). Using these strategies need not make care more costly (Roter & Hall, 1993), but it is unclear whether such “soft” concerns can motivate schools, graduate medical education, or health care plans to devote energy and resources to addressing these issues. The high level of trust that physicians have enjoyed in the past has been
reflective of society’s view of medicine as a valued profession and, once lost, may be difficult to reestablish.

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References


